



**The Victory Summit® event: Newly Diagnosed
Finding Your Way Around Parkinsonville**
Recorded on Feb 20, 2021
Davis Phinney Foundation

Leigh Cocanougher (Education Program Manager, Davis Phinney Foundation):
Today I have the pleasure of introducing Tom Palizzi. He is one of our amazing ambassadors at the Foundation and longtime friend. He lives, as some of you heard, just outside of Denver, Colorado. He is a YOPD council leader for us; if you search on our site for those, you can see all the past webinars. He's done a lot of videos for us. He has great bike advice. He has just all kinds of great resources on our site and he is a pedaling for Parkinson's pro and we're very happy and lucky that he's part of our teams. So, I am going to turn it over to him. I'll keep an eye on the chat and feel free to let us know if you have any questions, Tom. It's all yours.

Tom Palizzi (Davis Phinney Foundation Ambassador, YOPD Council Leader):
Okay. Thanks Leigh. Hello there everybody. And once again, my name is Tom Palizzi and today we're going to find our way around Parkinsonville. And though to my knowledge there isn't a city or town it's actually called Parkinsonville. It's a place that you'll see basically surrounds us all. I'll be cheating with my notes quite a bit, cause I have Parkinson's as well and whenever I get under stress like this, I start to freak out a little bit, as you probably recognize. Anyway, this session is for people who are diagnosed with Parkinson's disease, of course, it's for those who learned it yesterday, those that were told maybe a year ago, and those that have had it for 10 years or more like myself. Whether you qualify for AARP or YOPD, this session is for you. It's for your care partners and it's for anyone at any stage of their journey with Parkinson's.

This session is about finding your way in a new place, where to start, what to look for. It's about the people and the organizations dedicated to helping you, and it's about building a network and a wellness team that you can rely on. Mostly though it's about finding answers to the questions you probably didn't even know that you had. Hearing those words, "You have Parkinson's," is life changing as I'm sure you know. For some, it marks the end of a long and frustrating search to understanding the array of peculiar and seemingly disconnected symptoms you might've had. For others, it comes as a complete shock, trying to understand what it was your doctor just said. For all those though who hear these three words, that moment becomes a milestone; a time and a place where your life's journey encounters a detour. For most it's daunting, though for some, it can become an adventure. Parkinson's is not necessarily life-threatening as you might've heard earlier today, but what often disrupts movement, mobility, sensation, and cognition, symptoms and effects that get worse over time. You will hear if you haven't already today and previously that Parkinson's is not necessarily a death

sentence. In other words, people with Parkinson's die from other things. And most of us go on and live a long and fulfilling life.

I remember clearly those three words took me by complete surprise. The first thing that went through my mind was, "Oh my God, how long do I have to live?" Then just as quickly I recalled that Michael J. Fox had had Parkinson's for well over 10 years at that time, and he was still doing strong. In fact, he was still acting. The third thing that went through my mind was, "What the heck is Parkinson's anyway?" And with that, my journey had begun. Today, some 13 years later, I look back on that day in April and I can't help but wonder how different things would have been if I had known then what I know now, and that is what we'll talk about today as you learn how to find your way around Parkinsonville.

You know, you don't really look for Parkinsonville, it's more like you suddenly find yourself there. For me, it was like the Wizard of Oz. You feel like you've been uprooted by a tornado, spun around and about the sky, and then suddenly you're slammed to the ground in a strange place. If only Dorothy, or if only you, knew what to ask. All we really needed to do is tap our heels three times and say, there's no place like home. My friend, Lorraine Wilson imagined a special place more in line with Garrison Keillor, a place where the care partners are strong, the people who have Parkinson's are good looking and the children are all above average. A place not unlike Lake Wobegon where the sign along the road says, "Welcome to Parkinsonville, where people living with Parkinson's live, learn and thrive." As you'll see Parkinsonville is much closer to you than you might think.

Things are very different today than they were when I was diagnosed some 13 years ago. Over the past two decades, well-funded research has led to landmark discoveries, effective therapies and new treatments, all of which have produced volumes of information and unlike any other time in history, nearly every topic, issue, idea, basically everything related to Parkinson's is generally available on the internet. There are organizations promising hope through education and knowledge, better lives together, speeding a cure and how to live better. There are webpages and social media sites, blogs and podcasts, divas and doctors, videos, and books. There are thought leaders and scientists, preachers, and politicians, doctors and therapists, medications and treatments. There's even a World Congress that meets every three years, and the very special study group made up of researchers, doctors, chemists, and people living with Parkinson's. That special interest group: I attended the very first meeting of that at the World Parkinson's Congress, a few years back, and I was sitting next to a woman who was a researcher at the University of Kentucky. When I introduced myself, I was the person at the table who had Parkinson's. She said, I've been doing this for 10 years and I've never met someone with Parkinson's, you're the first person. That to me, registers in my head, how do we make sense of all this?

For the longest time, I thought my twilight career would be finding me in orange bib coveralls greeting folks at the door at the local Home Depot. Well, this certainly isn't the hardware store with, "Let me welcome you and your families and your friends to Parkinsonville." Recently, I surveyed my pedaling for Parkinson's indoor cycling class. I asked them to think back to the time when they were first diagnosed, I said, "What do you wish you knew then that you know now?" And an overwhelming majority wished they had the list of things to do and some guidance on where to find it. And that of course is in Parkinsonville. And hopefully today we'll figure out where to find those things. So, there are people who are previously familiar with PD, say family and friends might've had the disease. Many now had an idea of what questions to ask and like me, "I didn't even know what Parkinson's was."

Now. The biggest mistake I made was attempting to earn a PhD in Parkinson's overnight. I went Google crazy and in a couple of days, found myself in the hospital with an anxiety attack. Does that sound familiar to anybody? In hindsight, I've learned the best way to understand how to get around Parkinsonville is to view it in four general groups. The groups are what I call, "First things first," where you get your feet on the ground, your "Wellness team," because doctors will be important, realizing that there's "More than medical," what can I do to help myself? And the "Resources" that are out there for me to use? Keep in mind, these activities are not mutually exclusive and often many are happening simultaneously and that's okay.

So, we can take a look at these in a little more detail. First things first, the best advice I'd ever heard regarding those initial moments was simply breathe. Just take a minute and breathe and believe it or not that advice came to me only a couple of days ago. Now, as you start to explore Parkinsonville, you'll no doubt have questions and who better to ask than the experts. I like to point to the experts first, because that's where you can get the most knowledge you can in the shortest amount of time. And they can control how you see things, so rather than just hitting Wikipedia or Google searches, you never know what you might find, and it could be quite scary. Your best resources will come from a few knowledgeable and responsive organizations, non-profits that can address any and all the questions on as many topics as you like. With the latest information, they can help you quickly make sense of a situation and help you navigate to where it is you need to go next.

Well, the three most prominent organizations each contributes significantly to the Parkinson's community. They also have a unique position in and of themselves and a very unique perspective. In 2016, the National Parkinson's Foundation and the Parkinson's Disease Foundation merged to form the Parkinson's Foundation. They're best known for their comprehensive educational materials, support for early-stage research, and advocating for a Parkinson's community, they're a great place to start first. In fact, that's where I started. Now keep breathing. In 2000, the Michael J. Fox Foundation was formed with the sole mission of finding a cure to Parkinson's, the largest non-profit funder of Parkinson's research. In the world, the foundation has



invested nearly a billion dollars over the past 20 plus years. But as I came to understand more about Parkinson's, I realized, I couldn't just sit back and wait patiently for a cure. And as I moved further away from that first day, that day of being told, I was looking down the road ahead, and it became clear to me that the end of this journey would likely be years away, lots of years. I had to breathe again.

So, in a neat little neighborhood in Parkinsonville, you'll find a resource uniquely focused on the time between diagnosis and what may be years down the road. Founded in 2004, by former professional cyclist and Olympic medal winner Davis Phinney, the foundation that bears his name fills that void through their mission to help people live well with Parkinson's today, the organization provides focused webinars and events such as this Victory Summit today, along with an array of resources, with a network of more than 50 ambassadors like myself around the country, people with Parkinson's can reach out for individual personal support and we take great pride in helping our peers who are suffering from Parkinson's.

So those are really the big three that I call them, the big three organizations that can really be your big help. So, on the one end, you have the Parkinson's Foundation who can help with education at the front end and on the other end, you have the Foxx foundation still avidly seeking a cure. And of course, the Davis Phinney Foundation to help us through our the rest of our lives in between. So now you're ready to focus on your health and wellbeing. So, let's take a minute and breathe again before we get started

For decades anything related to our health was the exclusive domain of your doctor. Of course, given what we understood about life in general, we had little choice, but to see a medical doctor to treat or resolve those things that held us. Today, however, the doctor's office has evolved to keep up with the expansion of medical sciences and there are literally specialists for everything. No longer do rely on Marcus Welby MD. In fact, you'll build and lead a wellness team specifically for you. And you'll be the boss. Most general practitioners are not well-versed enough to care for progressively degenerative diseases like Parkinson's, you're looking for a neurologist and specifically a movement disorder specialist. We heard about how those guys operate this morning. From our friends in the nonprofit world, we can tap into resources they've developed to help us find movement disorder specialists nearby, medical schools with major universities are a good place to start. And in today's higher education, health professionals study to become therapists, chiropractors, pharmacists, dentists, dietitians, nutrition experts, you name it. You'll likely seek help from all of these people at some point in time. And the key to living well with Parkinson's, however, is to be more proactive and less reactive. You're not only the patient, you're a vital part of your team. In fact, once again, you are the team leader.

Wellness goes way beyond just the medical though. Your spiritual, social, and financial health are sometimes as important as the treatments and therapies you'll take. And now that you're pretty familiar with Parkinsonville, basically, it's time to organize your future. Health insurance will become even more important along with financial stability. So, finding a good attorney along with a solid financial manager and with their help, you can prepare a plan to see you and your family into the future. A good attorney could be like lawyers that practice elder care, and solid financial planners, again, very important to do with guiding you down the road. Stress and apathy are common among people with Parkinson's. Stress compounds our symptoms, and apathy can result in deep depression. Oddly enough, people with PD seem to thrive when they build groups of new networks. Support groups are typically well attended, active and dynamic and working together they can accomplish amazing things. So, the support group I run is really basically a cycling class where we meet Monday, Wednesdays and Fridays in the mornings and ride our bikes together.

There are countless, literally endless resources available in Parkinson's. There's a library with books about the science, the history, and even a book about ending Parkinson's. There's inspirational books abounding offering both common sense viewpoints along with a healthy dose of optimism. And of course, the internet plays host to clinical trial sites that match patients with research trials, such as the Foxx trial finder or the NIH clinical research trial system. There are numerous sites to help you find professional services, such as accountants, attorneys, financial planners, and insurance support, and dozens of movement disorder directories to help you find a specialist near you. And of course, near you can be relative these days. I think it's important that we consider that. Near you can be, for me, for example, I have people that attend my cycling class from each coast and every place in between. So near you no longer has to be the town that's closest by or the next biggest city. Through the advent of tele-health, you can actually meet with movement disorder specialists that might live a thousand miles away. You'll find support groups nearby and far away. Again, you can meet with them via zoom type products. And in our current virtual world, people are beginning to find their way into groups that fit them better, even though they might be in Florida and most everyone else might be in Denver, for example.

Look, we all know that exercise is good for us, but exercise goes well beyond simply being good for people with Parkinson's. In fact, there's currently a push to empower doctors to issue prescriptions for exercise for Parkinson's and other conditions to help those things to be covered by insurance. I've been cycling most all my life, not a racer or a long distance or endurance rider, but a fairly accomplished and skilled cyclist. I worked out regularly for years and was in a pretty good shape, but again, what's important, when I was diagnosed, my neurologist suggested I keep exercise in my regimen. In fact, she encouraged me to do more than that. She ordered me to exercise an hour daily, five to six days a week. I thought, "Wow." That wow has turned into a deep-rooted belief that exercise has helped me maintain a good life with minimal symptomatic limitations for the past 10 years. In particular, I've witnessed the benefits of



indoor cycling, not only personally, but with several people that have joined my pedaling for Parkinson's class. Both before COVID and now online, I've seen people come their first day on a walker or with a Walker.

And after a few weeks skipping into the room, hopping on a bike and off they go. Interesting how exercise and breathing go hand in hand isn't it? Parkinsonville is not only home to virtual places, but to real brick and mortar locations as well. Swimming pools, cycling studios, gymnasiums, and boxing clubs come to mind. But lately we're seeing new multi-purpose facilities pop up, "In Motion" in Cleveland, Ohio is a good example. A community-based center created specifically for people with Parkinson's, specialized trainers, dedicated staff and volunteers provide exercise, arts, support and education programs at no cost to the clients. And similarly, here in Denver, the Parkinson's Point provides a community space where people with Parkinson's are connected and empowered to live their best life.

I call this the ultimate guide. I think everybody calls it the ultimate guide, first produced in 2010, the Every Victory Counts® manual from the Davis Phinney Foundation literally instantly became a de facto standard, a guide to living with Parkinson's. The product of more than 40 leading specialists from an array of disciplines. The manual is in essence, the charter for Parkinsonville. I like this one, a comment I read in here, a quote, "It's honest, insightful, and inspirational. The EVC manual should be the very first thing newly diagnosed patients should have." And to that end, we actually delivered box loads of them to the hospitals here in Denver, where people were most likely to be diagnosed with Parkinson's right away.

When you're asked to show someone around the city you live in, you're probably pretty comfortable doing so. You probably take them to the more notable locations and you probably brag a little bit. I hope that you find the four steps to finding your way, help you along with your journey and that you become comfortable to lead newly diagnosed people that will follow you and I in the future. So again, looking at the four main focuses to finding your way in Parkinsonville, and of course getting a hold of that Every Victory Counts manual and using it, because that is very much the ultimate guide to finding your way.

So, 13 years ago, when I walked out that door, Parkinsonville was there, but there were no signs or directions or much help in any way. I discovered that five years before, an organization had formed in pledges to find a cure to the disease within 10 years. I thought, lucky me, I only have to deal with this for five years. Here it is so many years later. And as of today, they have yet to find that cure. But this is by no means a failure. What they have discovered was that they didn't know what they didn't know, and that created more focused paths for the researchers. In the meantime, we, the people of Parkinsonville seem to always be there for each other; something I noticed early along in my journey. The people I've met along the way have become and remain close



personal friends. By far it's the strangest phenomenon, I feel like I've known you all my life. So be safe, stay healthy and always hopeful.

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